Attitudes Towards Death and Dying in the East of England - Quantitative Report

Research to Inform the Development of Social Marketing Interventions on Palliative and End of Life Care

13 August 2010
# Contents

Summary findings ........................................................................................................... 1  

Background .................................................................................................................. 6  
  Aims and objectives ........................................................................................................ 8  

Methodology ................................................................................................................. 12  
  Fieldwork ..................................................................................................................... 12  
  Sampling ....................................................................................................................... 12  
  Sample profile and weighting ...................................................................................... 13  
  Questionnaire design .................................................................................................... 14  
  Interpretation of the data ............................................................................................... 14  

Comfort talking about death ......................................................................................... 16  
  Comfort with discussing death generally ..................................................................... 16  
  Comfort with discussing one’s own death ..................................................................... 18  

Experience of death ....................................................................................................... 22  
  Funerals ....................................................................................................................... 22  
  Death of a loved one ..................................................................................................... 24  

Experiences of care received ......................................................................................... 27  
  Medical and nursing care ............................................................................................. 27  
  Social Services ............................................................................................................. 30  
  Levels of support .......................................................................................................... 33  

Planning for end of life care ......................................................................................... 36  
  Discussing preferences ................................................................................................. 36  
  Making plans ................................................................................................................ 39  
  Preferred sources of information .................................................................................. 43  
  Ability to plan ............................................................................................................... 44  

Preferences for end of life care ..................................................................................... 48  
  Preferred place to die .................................................................................................... 48  
  Key aspects of end of life care ...................................................................................... 51
Appendices ........................................................................................................ 57
  Statistical reliability .................................................................................. 57
  Questionnaire .......................................................................................... 59
Summary findings
Summary findings

Methodology

We conducted a postal survey across the East of England. In order to allow comparisons with the rest of the country we also included a national sample. Addresses both in the East of England and the rest of the country were selected at random. In total, 693 responses were received from the East of England (a response rate of 28%) and 332 from the rest of England (a response rate of 27%). For further details please page 13.

Comfort discussing death

The majority of people in the East of England feel comfortable discussing death, both generally (73% are very or fairly comfortable) and in relation to their own mortality (69%). Furthermore, this level of comfort appears to be marginally higher than the rest of England overall (67% and 56% are comfortable about these respective issues).

Women are more likely than men to say they are uncomfortable, both when discussing death generally (15% and 8% respectively) and also specifically in relation to themselves (20% and 10% respectively). People living with a long-term condition generally feel more comfortable than those without such a condition (83% and 71%).

Discussing end of life preferences

In terms of end of life preferences, people in the East of England are also more likely to have discussed their wishes than people living in the rest of the country. Just over half of people in the East (54%) have discussed at least one of the following: preferences relating to religion, dignity, preferred location of death, privacy/peace, and medical and nursing care. This compares to 44% of people in the rest of England.

Levels of comfort are relevant; those who say they feel comfortable discussing death are far more likely to have discussed at least one of these aspects of end of life care (61%) than those who are uncomfortable (28%). Recent experience is also relevant; other than religious and/or spiritual preferences, people who have experienced the death of a loved one in the
last five years are more likely to have discussed all of these matters than those who have not lost someone close to them in that time.

The results suggest that faith can make discussing these issues easier; those without a religion are twice as likely to feel uncomfortable broaching the subject of their own death as those who follow a religion or belief system (25% and 13% respectively). People who follow a religion are also more likely to have made some form of plan than those who do not.

The most common reason given for not discussing end of life preferences is the feeling that death is a long way off, mentioned by just under half (46%). A fifth (21%) say they do not want to upset their loved ones by discussing it. This is particularly pertinent for the elderly and people living with long-term conditions. Over half (56%) of people aged 75+ cite fear of upsetting others, while people living with long-standing conditions are significantly more likely than people without such a condition to say it is because they do not want to upset their loved ones (34% compared to 18%) and that there is no one for them to discuss it with (14% versus 3%).

Making plans

Two in three people (68%) say they have taken some form of practical action to plan for the end of their life. As well as feeling more comfortable discussing death, and being more likely to make their preferences known verbally, people in the East are more likely than the rest of the country to have made plans (68% versus 55%). The plan most commonly made is the writing of a will (43%), followed by having an organ donor card (34%) and arranging a funeral (27%). Men are more likely to have made some form of arrangement than women (74% and 65%), particularly a will, plans for their funeral or the financial aspects of their end of life care.

While the likelihood of making plans rises with age, as would be expected, there remains a significant proportion of people aged 75 or over who have not made plans in some areas. Less than half (48%) have planned their funeral, just 14% have planned the financial side of their end of life care, and one in 11 (9%) have not made any plans of the plans listed.
Helping people to make plans

The factor that most people think would help them plan is to make the process easier for their family (79% agree). Three quarters (76%) agree that easy access to information explaining how to plan would help encourage them to take action, although younger age groups are more likely to agree (82% of 16-54 year olds compared to 70% of those aged 55+).

Friends and family (54%) and GPs (47%) are the two most commonly preferred sources of information. People aged 75 or older are least likely to want information provided to them by a healthcare professional (41% compared to 55% of other age groups).

Generally people have greater confidence in their ability to plan for a funeral (81% are very or fairly confident), than for financial support (66%) or getting the right sort of care and support (62%). Men are generally more confident in these matters than women.

Funerals

The vast majority (97%) have been to the funeral of someone close to them but fewer have actually seen a dead body (71%). Younger age groups are less likely to have seen a dead body than other age groups. Less than half (46%) of people aged between 25 and 34 have seen a dead body, compared to 90% of people aged 55 and over.

Just under half agree that it is suitable for children under the age of 12 to attend funerals, while just under a quarter disagree. However, it is possible that discomfort can act as a barrier; those who say they are uncomfortable discussing death are less likely to agree it is suitable for people of this age to go to a funeral.

End of life care preferences

For the majority, the preferred location to die is at home (55%), people aged 75 or over are most likely to say this (69%). However, the majority of respondents prioritise receiving the correct care and support over dying in the place of their choice (59% and 37% respectively). Being with friends and family (31%) and being pain free (27%) are prioritised as the most important factors in end of life care.
While a large majority (87%) say that they would want to be informed of a terminal diagnosis, there remains a reluctance to acknowledge it among a section of the most elderly; around one in seven (15%) people aged 75 or older would prefer not to know.

**End of life care received**

Just under half of respondents (48%) who have lost a loved one in the last five years say that the care provided by the NHS was either very good or good, while 15% say it was poor. In terms of the care provided, NHS staff are the most commonly cited positive aspect of care but are also the most frequently mentioned criticism. People with long-term conditions are more likely to be critical of the care and support provided by the NHS than those without such conditions.
Background
Background

End of Life Care

Over recent years, as the NHS has placed greater emphasis on patient choice, the profile of end of life care has become more prominent within the health service. In 2008 the Department of Health published an End of Life Care Strategy aiming to improve the provision of care to those approaching the end of life, as well as those who care for and support them. In addition, the Department has committed additional funding to end of life care services, over the next 2 years, to help implement the End of Care Pathway, represented below.

However, against this backdrop of increased patient choice, it has been recognised in recent years that there is a gap between people's wishes for the care they receive at the end of their life and the reality that is experienced by much of the population. This gap is particularly
noticeable when it comes to the location in which people die; currently between 56 and 74 per cent of people express a wish to die at home, yet 58% die in an acute hospital\(^1\).

Previous research\(^2\) has shown that a key barrier preventing the fulfilment of people's wishes around end of life care is the societal taboo that exists around death and dying. This taboo can inhibit people from discussing the care that they would like to receive and making their needs and preferences known.

This lack of open discussion means it is very difficult for the NHS to plan services. To try to address this issue, the End of Life Strategy highlighted a need for increased awareness and discussion around the plans people can make, in order to make it easier for people to talk about their preferences.

The East of England Strategic Health Authority has put in place a clinical vision aimed at transforming NHS services in the area; *Towards the best, together*\(^3\). So far, a revised strategy has been published, a dedicated website has been launched and ten clinical programme boards, including one for Palliative and End of Life Care, have been set up. ‘*Towards the best, together*’ sets out several key areas of work for the Palliative and End of Life Care programme board, including:

- Delivering world class standards in meeting choice of place of death;
- Ensuring needs assessments and advance care planning for all identified as being in the last year of their life; and
- Working with the public and partners to raise awareness of end of life issues.

By addressing these actions, as well as others set out in the vision, the programme board aims to promote several key messages including:

- Helping people to talk about death more openly and understand the challenges faced families and individuals at the end of life; and
- Enabling people to choose where they want to die.

---

2. Examples can be found in the appendices of the Scoping Study Report completed as part of this research.
Overall, the East of England SHA has set in motion several actions to help tackle issues raised at end of life. The aims, set out above, for the Palliative and End of Life Care programme board, demonstrate the commitment of the SHA to ensuring high quality end of life care for all.

Aims and objectives

In the light of the taboo around death, and the difficulties that this causes when trying to put appropriate care into place, the East of England Strategic Health Authority (SHA) has commissioned Ipsos MORI to undertake insight research to inform social marketing interventions. These interventions will be aimed at raising awareness of End of Life care and the plans which people can make in relation to this subject.

The research has been designed to engage both residents and healthcare professionals to help inform the design and delivery of the intervention(s). It explores attitudes towards discussing and planning for death and provides insight as to what would encourage people to plan for the end of their life and the care they want to receive. The overall aim of the research is to:

- allow the population in the region to plan more effectively for the end of their lives;
- permit the SHA to improve the delivery of high end care; and
- help increase the chance that the wishes of its residents can be fulfilled at the end of their lives.

To meet these aims, the specific objectives of the research can be summarised as follows:

- To explore attitudes towards talking about and planning for death;
- To provide insight into why people do not make plans for their death and explore how this can be overcome;
- To inform the content and delivery of two social marketing campaigns around the issues of talking about and planning for death; and
- To enable, to some extent, the evaluation of the interventions.
In order to meet these objectives, there were three distinct phases of the research. These included:

- A scoping study of the existing literature on the subject
- A quantitative survey of residents
- Qualitative discussion groups with the general public and healthcare professionals

This report presents the findings of the quantitative element of the research with the general public. Separate chapters have been produced for the scoping study and qualitative element, while all three have been brought together in the Social Marketing and Interventions section. The purpose of the quantitative survey is set out below.

**Baseline and insight data – quantitative survey**

In order to allow any intervention to be accurately evaluated, baseline measures of key attitudes and behaviours are needed. These measures can be tracked over time to test the effectiveness and efficiency of any social marketing intervention. Key measures for this area include talking about death and planning for death.

A quantitative baseline survey also enriches our understanding of the situation and, in combination with qualitative methods, is able to present a comprehensive picture of where people are, in terms of their attitudes and behaviours. This means that any social marketing intervention is based on a clear starting point and any aims and objectives can clearly be developed on how far people need to travel (in terms of in the direction of the behaviour it is hoped they will exhibit). Furthermore, national data on this subject currently exists but does not allow for meaningful comparisons between the situation in the region and the national picture.

Further objectives were therefore identified specifically for the quantitative element of this research. They can be summarised as follows:

1. To inform the final design and focus of subsequent qualitative research;

---

4 Such as the 2009 Dying Matters Coalition survey
2. To provide a baseline measure that can be used for evaluation of subsequent interventions both in service design and future social marketing interventions, e.g. questions on comfort talking about death; and

3. To allow comparisons to be drawn between the national results and the East of England and to identify any differences.
Methodology
Methodology

Fieldwork

Quantitative fieldwork was carried out between 26th March and 20th July 2010. A self-completion postal survey was mailed out to 2,500 randomly selected addresses from the Postcode Address File (PAF), followed by two follow-up reminders on 11th June and 2nd July to those households which had not replied.

In order to allow comparisons of the results of this survey to the picture elsewhere in the country, a national sample (not including the Eastern region) was also included in the fieldwork. This additional sample will also help isolate and separately measure the impact of any future social marketing initiative. The recent survey commissioned by the Dying Matters Coalition in 2009, while useful, does not provide insight at the regional level. We will, however, make comparisons with this where appropriate.

Questionnaires were therefore mailed out to 1,250 addresses across the rest of England (not including the Eastern region) using the same sampling approach and the same dates for reminders.

Sampling

Addresses both in the East of England and the rest of country had an equal chance of being selected in the sample. Across the East of England, addresses were selected at random using a '1-in-n' approach from the Royal Mail Small User Postcode Address File\(^5\). The sample was stratified by Primary Care Trust (PCT) and selected proportional to population size of each PCT to ensure a distribution matching that of the region.

For the sample for the rest of the country, postcodes were selected with probability proportional to the number of addresses in each postcode, and then addresses were selected within each selected postcode. The sample was stratified by Strategic Health Authority and then by Primary Care Trust.

---

\(^5\) It should be noted that the PAF covers c. 99% of all addresses.
**Sample profile and weighting**

In total, 693 responses were received from the East of England (a response rate of 28%) and 332 responses from the rest of England (a response rate of 27%). To help rectify for non-response, data is weighted to the profile of the known population on age, gender, working status and Primary Care Trust (Government Office Region for the national sample).

The chart overleaf shows the profile of the sample before and after weighting.

The table below shows the profile of the samples for the East and the rest of the country, both before and after weighting has been applied.

<table>
<thead>
<tr>
<th>Demographic category</th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unweighted (%)</td>
<td>Weighted (%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>32</td>
<td>47</td>
</tr>
<tr>
<td>Female</td>
<td>65</td>
<td>50</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-24</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>25-34</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>35-54</td>
<td>33</td>
<td>34</td>
</tr>
<tr>
<td>55-64</td>
<td>22</td>
<td>15</td>
</tr>
<tr>
<td>65+</td>
<td>31</td>
<td>20</td>
</tr>
<tr>
<td><strong>Long-term condition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32</td>
<td>26</td>
</tr>
<tr>
<td><strong>Tenure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household owner / part owner</td>
<td>72</td>
<td>69</td>
</tr>
<tr>
<td>Rent - private</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Rent - social</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In full / part time employment</td>
<td>48</td>
<td>62</td>
</tr>
<tr>
<td>Not in full / part time employment</td>
<td>48</td>
<td>35</td>
</tr>
</tbody>
</table>
Questionnaire design

The questionnaire was developed collaboratively between Ipsos MORI and the East of England SHA. The questionnaire used in the Dying Matters Coalition survey of 2009 was used to inform the development of the questionnaire. All completed responses were scanned. A copy of the questionnaire can be found in the appendices.

Interpretation of the data

A sample rather than the entire population of the region took part in the research. Consequently, all results are subject to sampling tolerances, which means that not all differences are significant. All comparisons made between subgroups are statistically significant, unless stated otherwise. A guide to statistical reliability is provided in the appendices.

As the main audience of interest is the East of England population, all figures relate to the East of England findings, unless stated otherwise. Where bar charts have been used to show the prevalence of a view, preference or behaviour, results are given both for the Eastern and national samples as a comparison. A red oval indicates that a difference in a finding between the two samples is statistically significant.

Where percentages do not sum up to 100, this may be due to computer rounding, the exclusion of ‘don’t know/not stated’ response categories, or because participants could give multiple answers. Throughout the report, an asterisk (*) denotes any value of less than half of one per cent, but greater than zero.

In this report, reference is made to ‘net’ figures. This represents the balance of opinion on attitudinal questions, and provides a useful means of comparing the results for a number of variables. In the case of a ‘net agree’ figure, this represents the percentage in agreement with a particular issue or statement, less the percentage in disagreement. For example, if 40 per cent agree with a statement and 25 per cent disagree, the ‘net agree’ figure is +15 points.
Comfort talking about death
Comfort talking about death

This section examines how comfortable people feel in discussing death, both in general but also specifically about their own death.

The key findings of this chapter are as follows:

- A majority of respondents say that they are comfortable discussing death, including their own death.
- Women are more likely than men to be uncomfortable talking about death.
- Age, faith and state of health can all have an impact on how comfortable people feel discussing these issues.

Comfort with discussing death generally

The majority (73%) of people say they feel comfortable discussing death while one in nine (11%) are fairly or very uncomfortable. Across the rest of England, two thirds (67%) feel comfortable having these discussions. While there appears to be a slightly higher level of comfort in the Eastern region, we cannot say this is a statistically significant difference due to the sample sizes involved. Findings from the 2009 Dying Matters Coalition survey found broadly comparable results; 68% of British people said they were very or fairly comfortable.
Comfort with discussing death

Q1. Which of the following best describes how you feel talking about death generally?

An equal proportion of men and women feel comfortable talking about death (76% and 72% respectively). However, women are more likely to say they feel uncomfortable having these discussions (15% versus 8% of men).

People living with a long-term condition are more likely to feel comfortable talking about death (83% compared to 71% of those without a condition).
Q1. Which of the following best describes how you feel talking about death generally?

<table>
<thead>
<tr>
<th></th>
<th>% Very comfortable</th>
<th>% Fairly comfortable</th>
<th>% Very uncomfortable</th>
<th>% Neither/nor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (224)</td>
<td>36</td>
<td>40</td>
<td>15</td>
<td>53</td>
</tr>
<tr>
<td>Female (447)</td>
<td>30</td>
<td>43</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>16-24 (14)</td>
<td>28</td>
<td>29</td>
<td>11</td>
<td>28</td>
</tr>
<tr>
<td>25-34 (54)</td>
<td>33</td>
<td>42</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>35-54 (231)</td>
<td>33</td>
<td>41</td>
<td>14</td>
<td>9</td>
</tr>
<tr>
<td>55-64 (153)</td>
<td>39</td>
<td>38</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>65+ (217)</td>
<td>30</td>
<td>46</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>Long-standing condition (219)</td>
<td>41</td>
<td>42</td>
<td>9</td>
<td>44</td>
</tr>
<tr>
<td>No long-standing condition (448)</td>
<td>30</td>
<td>41</td>
<td>15</td>
<td>11</td>
</tr>
</tbody>
</table>

There is some indication that faith can help make these discussions easier; people who follow a religion or belief system are more likely to be comfortable discussing death (75%) compared to those who do not (64%).

**Comfort with discussing one’s own death**

In order to explore whether people feel differently towards discussing death as a general concept rather than their own mortality, a question was asked in relation to their own death. Findings are broadly consistent between these two issues, with seven in ten (69%) saying they are comfortable discussing their own death, and one in seven (15%) uncomfortable. This is a higher level of comfort when compared with the rest of the country where just over half (56%) are comfortable.
Q12. Which of the following best describes how you feel talking about your own death?

<table>
<thead>
<tr>
<th>Description</th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very comfortable</td>
<td>31%</td>
<td>24%</td>
</tr>
<tr>
<td>Fairly comfortable</td>
<td>38%</td>
<td>33%</td>
</tr>
<tr>
<td>Fairly uncomfortable</td>
<td>11%</td>
<td>13%</td>
</tr>
<tr>
<td>Very uncomfortable</td>
<td>4%</td>
<td>22%</td>
</tr>
<tr>
<td>Neither/nor</td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td>Not stated</td>
<td>15%</td>
<td>33%</td>
</tr>
</tbody>
</table>


As is the case with talking about death generally, women are more likely to say they feel uncomfortable discussing their own death (20% compared to 10% of men). Other key differences in subgroups include:

- people 75 and over show the lowest levels of discomfort (8%);
- people aged 55-64 are the most likely age group to say they feel comfortable (77%);
- those living with a long-standing condition are more likely to be comfortable (77%) compared to those without a condition (67%); and
- those who do not follow a religion are more likely to be uncomfortable discussing these issues than people with faith (25% and 13% respectively).
Comfort with discussing one’s own death – key demographic groups

Q12. Which of the following best describes how you feel talking about your own death?

<table>
<thead>
<tr>
<th></th>
<th>% Very comfortable</th>
<th>% Fairly comfortable</th>
<th>% Neither nor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male (224)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (447)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-24 (14)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-34 (54)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-54 (231)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64 (153)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65+ (217)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long-standing condition (219)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No long-standing condition (448)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Base: 693 adults living in the East of England, individual base sizes in brackets, fieldwork dates 26th March – 20th July 2010
Experience of death
Experience of death

The following section covers people’s experience of death; whether they have attended a funeral, their view towards children attending them, and whether they have lost a loved one in recent years.

The key findings of this chapter are as follows:

- While there is no difference, by age, in the likelihood of attending a funeral, people in the younger age groups are less likely to have seen a dead body.
- Nearly half of respondents say that it is appropriate for a child under 12 to attend a funeral, while 23% disagree.
- Over half of respondents have experienced the death of a close friend or family member in the last five years.

Funerals

Over nine in ten (97%) have been to the funeral of a friend, relative or work colleague. This is consistent with the results of the national sample (96%) and also the Dying Matters coalition survey in 2009 (94%).

While the vast majority have been to a funeral, fewer have actually seen a dead body. Seven in ten (71%) report having seen a dead body, which is consistent with the national sample (74%) and the Dying Matters Coalition survey (69%).
Experience of death

Q2. Have you ever attended the funeral of a family member, a friend or work colleague?

97%

Q3. Have you ever seen a dead person?

71%


Men are more likely to have been to a funeral (100% compared to 97% of women) but there is no difference by age.

Conversely, people of an older age are more likely to have seen a dead body with 90% of people aged 55 or older saying they have. This is much less common among the young; less than half (46%) of those aged between 25 and 34 say they have seen a dead person.

Around half (48%) agree that it is appropriate for children aged under 12 to attend a funeral, while just under a quarter (23%) disagree. Over a quarter (28%) do not give a view either way. This is in line with the findings of the national sample, where 49% agree and 21% disagree, and also the Dying Matters Coalition survey (46% agreed).
As was the case in the 2009 Dying Matters Coalition survey, men are more likely to believe it is appropriate for children under 12 to attend than women (54% versus 44%). There are no differences in views between different age groups. Those who consider themselves atheist or having no religion are most likely to feel that it is appropriate for children younger than 12 to go to funerals (73% and 60% agree respectively).

People who say they are comfortable discussing death show greater support for children under 12 attending funerals than those who are uncomfortable (53% versus 29%).

**Death of a loved one**

Just over half (56%) of respondents say they have experienced the death of a close friend or family member in the last five years.
People aged 55 to 64 are the most likely of all age groups to say they have lost someone in the last five years (64% say they have).

Those who care for someone, but not in a professional capacity, are more likely to have experienced the death of someone close (69% compared to 54% of those who do not provide this caring role). People with a long-standing condition are also more likely to have lost a loved one than someone without a long-standing condition (65% and 55% respectively).
Experiences of care received
Experiences of care received

People who have experienced the death of someone very close to them in the last five years were asked to rate different aspects of the care and support they received – from the NHS and Social Services - during that time. This section of the report explores the rating they give these services and the reasons behind their views.

The key findings of this chapter are as follows:

- Just under half of respondents who have lost a loved one in the last five years say that the care provided by the NHS was either very good or good, while 15% say it was poor.

- In terms of the care provided, NHS staff are the most commonly cited positive aspect of care but are also the most frequently mentioned criticism.

- More respondents are positive rather than negative about the care and support received from Social Services, but the majority say it was not applicable or did not give a response.

- People with long-term conditions are more likely to be critical of the care and support provided by the NHS than those without such conditions.

Medical and nursing care

Of the 56% who have experienced the death of a loved one in the last five years, more hold favourable rather than negative views towards the medical and nursing care the patient received from the NHS, in the last days before they died. Just under half (48%) rate this care as very good or good and one in seven (15%) feel it was poor or very poor. A quarter (24%) did not give an opinion or felt NHS medical or nursing care was not applicable.

The rating in the East of England is slightly below that of the rest of the country where 59% say the medical and nursing care was very good or good.
Q5. How would you rate the medical and nursing care from the NHS they received in the last days before they died?

People aged over 75 are most favourable about NHS care received, with just under three quarters (72%) saying it was good or very good and just three per cent poor or very poor. Conversely, people with a long-standing condition are more likely to rate it as poor (22%). This is in contrast to the rest of the country where people with a long-term condition are actually more positive about the service they received (70% rate it as good or very good compared to 55% of people without a long-term condition).

People whose loved one had received care from the NHS were asked to explain why they gave a particular rating. The most common reason given for a positive rating is the work of the staff and nurses (cited by 43% of those who rate the care as either good or very good).
Reasons for positive views towards NHS care

Q6. Why do you say that? (that NHS medical/nursing care was good/very good)

Top 7 responses

- The staff/nurses were very good/kind/caring/helpful: 43%
- Took care/time with relatives/explained things to relatives: 11%
- Hospital care was very good/excellent: 7%
- Died at home/nursing home/hospice: 6%
- Treated with dignity/respect: 6%
- Everything possible was done: 4%
- District Nursing support excellent: 4%
- Not stated: 24%

Base: 214 adults living in the East of England who have experienced the death of a loved one in the last five years and rate NHS care as good/very good, fieldwork dates 26th March – 20th July 2010

While views are relatively positive about the staff involved, it is also the most common cause of complaint; of those who rate the care as either poor or very poor, two in five (39%) put this down to a lack of time or attentiveness from the staff. Just under a quarter (23%) say it was because of the quality of the medical care received, while one in six (16%) blame waiting times.
Social Services

Ratings of the care and support received from social services are lower than those given for the NHS. One in five (20%) say it was very good or good while one in nine (11%) believe it was poor or very poor. This is a net score of +9% compared to +32% given to NHS services received; 48% rate the NHS care and support as good and 15% as poor.

Over half (56%) did not give an opinion or felt that care and support from social services was not applicable.

While the proportion giving a positive rating is similar between the Eastern region and the rest of the country, people living in the East of England are more likely to say the care and support from social services was poor (11% compared to 4% elsewhere).

---

6 The net score represents the percentage rating the service as either good or very good, less the percentage rating it as poor or very poor.
Q7. And how would you rate the care and support they received from social services in the last days before they died?

As with NHS care, people aged over 75 are most positive; the net rating is +44% compared to +9% overall. Men are more positive than women; their net rating is +16% compared for +4% of women.

As with the care received from the NHS, the aspect of the care provided by social services which is most highly praised is the work of the staff (mentioned by 21% of those who say the care was good).
Reasons for positive views towards social services care and support

Q8. Why do you say that? (that social services care/support was good/very good)

Top 3 responses

- Nurses/Macmillan nurses/staff were good/caring/helpful: 21%
- Social services were good/there when needed: 12%
- Limited contact/one visit/only came to assess need: 10%
- No response: 36%

Base: 89 adults living in the East of England who have experienced the death of a loved one in the last five years and rate social services care/support as good/very good, fieldwork dates 26th March – 20th July 2010

The most common complaint about social services, on the other hand, is that no care was received from them, mentioned by over a third (37%). One in six (17%) who say the care was poor blame this on the stress that the experience caused them.
Of those who said that social services were not applicable, the most common reasons given were that social services were not involved (11%), that it was a sudden death (9%), that they were not aware of any involvement from social services (5%) or that the individual died abroad (5%).

Levels of support

When asked for their views on the level of support received from the NHS and social services, the largest proportion giving an answer are those who say it was not applicable or who did not give an answer (32%). Of those who do give a view, more are positive than negative; 30% agree it was sufficient compared to 14% who disagree.
Q9. Do you agree or disagree that you and your family received enough support from NHS and social services during and after this difficult time?

Key differences by demographic subgroup are as follows:

- People aged 75 or over are most likely to agree they received enough support (45%)
- Those with a long-term condition are more critical than people without a long-term condition (21% and 11% disagree they received enough care respectively)
- People who feel comfortable talking about death in general are more positive about the support they received than those who are uncomfortable (net agreement is +20% and +1% respectively).
Planning for End of Life Care
Planning for end of life care

This section covers the discussions people have had around end of life care, the actions they have taken and what would help them to make plans.

The key findings of this chapter are as follows:

- Just over half of people have discussed their preferences on at least one aspect of end of life care in relation to religious preferences, dying with dignity, preferred location of death, privacy and peace, and medical and nursing care. People in the East of England are more likely to have discussed at least one of these than elsewhere in the country.

- The most common reason given by respondents for not having discussed their end of life plans is that death feels a long way off.

- Over two thirds of respondents have made some kind of plan for their death (again, higher than the rest of England). The most common form of plan is to have made a will. Men and older people are more likely to have made plans than women and the young.

- Making the process of dying easier for family is a greater motivation to plan than getting the care or funeral of choice.

- Access to information about how to plan for the end of their lives is seen as a greater help than someone helping them to write an end of life care plan.

- Friends and family are the most common preferred source of information, followed by doctors.

- Respondents are more confident about their ability to plan for their funeral than their ability to plan for financial support or to plan to make sure that they receive the right kind of care.

Discussing preferences

When prompted with the list of end of life care preferences shown in the following chart, just over half (54%) have discussed at least one of them, compared with two in five (44%) in the rest of the country. People are most likely to have discussed their spiritual and religious
preferences and their wish to die with dignity (38% and 37% respectively). This is followed by the preferred place to die (discussed by 29%), privacy and peace and medical and nursing care (both considered by around a quarter of people (26%).

The same patterns emerge for the rest of the country, although people in the East are more likely than those in the rest of England to have discussed their wishes on all of these issues.

### Discussing end of life wishes

Q13. Have you ever discussed what your wishes would be, in relation to each of the following, if you did not have much time left to live?

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Yes – have discussed it with someone (East)</th>
<th>Yes – have discussed it with someone (Rest of England)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any spiritual and religious preferences</td>
<td></td>
<td>38%</td>
</tr>
<tr>
<td>Dying with dignity – e.g. respectful care and support</td>
<td></td>
<td>37%</td>
</tr>
<tr>
<td>Where you would prefer to die</td>
<td></td>
<td>29%</td>
</tr>
<tr>
<td>Privacy and peace</td>
<td></td>
<td>29%</td>
</tr>
<tr>
<td>Medical and nursing care</td>
<td></td>
<td>26%</td>
</tr>
<tr>
<td>Discussed at least one of these</td>
<td></td>
<td>26%</td>
</tr>
<tr>
<td>Not discussed any</td>
<td></td>
<td>21%</td>
</tr>
</tbody>
</table>

As indicated in the following chart, those who say they are comfortable discussing their own death are more likely to have discussed wishes around all of these aspects of end of life care, when compared with people saying they are uncomfortable having these discussions.
Discussing end of life wishes

Q13. Have you ever discussed what your wishes would be, in relation to each of the following, if you did not have much time left to live?

- Any spiritual and religious preferences
- Dying with dignity – e.g. respectful care and support
- Where you would prefer to die
- Privacy and peace
- Medical and nursing care

Discuss at least one of these

Not discussed any

Furthermore, recent experience is also likely to have an impact on the action people take; other than religious and/or spiritual preferences, people who have experienced the death of a loved one in the last five years are more likely to have discussed each of these matters than those who have not lost someone close to them in that time.

People with a long-standing condition are more likely to have had at least one of these discussions (62% versus 53% of people with no condition). There is no difference in gender and little difference in age, however.

People who say they do not follow a religion or belief system are actually more likely to have discussed their spiritual or religious preferences (48% compared to 36% of those with some form of faith).

Of the 42% of people who have not discussed any of these end of life issues, there are no differences by gender or age. However, as already discussed, those who have not experienced the death of someone they care for in the last five years are less likely to have had these discussions than someone who has (50% and 37% respectively have not discussed any issue).

The most common reason given for not discussing end of life preferences is the feeling that death is a long way off, mentioned by just under half (46%) of those who have not broached
any of these subjects. One in five (21%) are concerned that it would upset those close to them, while one in six (17%) feel they are too young to discuss death.

### Reasons for not discussing end of life wishes

Q14. Which of these statements best describes why you have not discussed any of these issues with anyone?

<table>
<thead>
<tr>
<th>Reason</th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death feels a long way off</td>
<td>62%</td>
<td>38%</td>
</tr>
<tr>
<td>I’m concerned that it may upset people close to me</td>
<td>21%</td>
<td>24%</td>
</tr>
<tr>
<td>I am too young to discuss death</td>
<td>17%</td>
<td>23%</td>
</tr>
<tr>
<td>I don’t feel comfortable talking about death</td>
<td>14%</td>
<td>17%</td>
</tr>
<tr>
<td>Other people do not want to talk to me about my death</td>
<td>12%</td>
<td>17%</td>
</tr>
<tr>
<td>There is no one available for me to talk to about death</td>
<td>5%</td>
<td>5%</td>
</tr>
</tbody>
</table>

The most common reasons given by people aged 16 to 34 are that death feels a long way off (62%) and that they are too young to talk about it (38%). However, the feeling that the prospect of death is too far in the future to think about, is not exclusive to the young; one in five (22%) people aged 75 or over also state this reason. The most common reason given by people aged 75 or over, however, is that they fear upsetting people close to them (cited by 56%). It should be noted, however, that these findings are based on small sample sizes (25 people aged 75+ and 33 aged 16-34) and so should be treated with some caution.

Respondents in the East of England living with long standing conditions are significantly more likely than people without such a condition to state that they have not discussed such matters because they do not want to upset their loved ones (34% compared to 18%) and that there is no one for them to discuss it with (14% versus 3%).

### Making plans

As with discussing end of life preferences, respondents in the East of England are more likely to have made plans for the end of their lives than those in the rest of the country; 68%
in the East say that they have made some form of plan for their death, compared with 55% elsewhere.

The plan most commonly made is to have written a will. However, once again those in the East of England are more likely to have done this than elsewhere in the country (43% compared with 34%). A third (34%) have registered as an organ donor and over a quarter (27%) have made plans for their funeral. Across the East and the rest of England, the least common form of preparation is a living will (undertaken by 8% and 7% respectively).

**Planning for end of life**

Q15. Have you made arrangements for any of the following?

<table>
<thead>
<tr>
<th>Arrangement</th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>A will</td>
<td></td>
<td>43%</td>
</tr>
<tr>
<td>An organ donor card (registered as an organ donor)</td>
<td></td>
<td>34%</td>
</tr>
<tr>
<td>My funeral wishes/plan</td>
<td></td>
<td>27%</td>
</tr>
<tr>
<td>Written wishes about organ donation</td>
<td></td>
<td>18%</td>
</tr>
<tr>
<td>My plan for how I would support myself financially when I am dying</td>
<td></td>
<td>10%</td>
</tr>
<tr>
<td>Wishes / preferences about end of life care if I become unable to decide for myself ('living will'/'advance care plan')</td>
<td></td>
<td>8%</td>
</tr>
<tr>
<td>None of these</td>
<td></td>
<td>27%</td>
</tr>
<tr>
<td>Made any plan</td>
<td></td>
<td>36%</td>
</tr>
</tbody>
</table>


In the East of England, men are significantly more likely than women to have made arrangements for the end of their lives (74% and 65% respectively have made some form of plan). Furthermore, men are more likely than women to have written a will (47% versus 39%), made plans for their funeral (31% versus 23%), and to have planned to support themselves financially whilst dying (15% compared with 5%). This is actually in contrast to the rest of the country where 53% of men have made a plan, compared to 60% of women.

Prevalence of making plans also rises with age; four in five people (79%) aged 55-74 have made some form of plan while nine in ten (89%) of those aged 75 and over have, as indicated in the following chart.
Planning for end of life

Q15. Have you made arrangements for any of the following?

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Made any plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aged 16-24</td>
<td>28%</td>
</tr>
<tr>
<td>Aged 25-34</td>
<td>60%</td>
</tr>
<tr>
<td>Aged 35-54</td>
<td>67%</td>
</tr>
<tr>
<td>Aged 55-64</td>
<td>79%</td>
</tr>
<tr>
<td>Aged 65-74</td>
<td>79%</td>
</tr>
<tr>
<td>Aged 75+</td>
<td>89%</td>
</tr>
</tbody>
</table>

As might be expected, it is the oldest in society who are most likely to have carried out some of the key actions; of people aged 75 and over, four in five (81%) have written a will, half (48%) have planned their funeral and one in five (21%) have made a living will. However, just one in seven (14%) have planned how they would support themselves financially when they are dying. This age group are also least likely to have made plans around organ donation (just 15% have registered as a donor, compared to 34% overall).

Moreover, as is the case with discussing these issues, there appears to be a correlation between comfort and taking action; people who feel comfortable discussing death (72%) are considerably more likely to have made at least one plan than those who are not (54%). Those who follow no religion or belief system are most likely not to have made any plans (38% compared to 26% of people who follow a faith).

As with discussing end of life matters, recent experience of death is relevant; people who have lost a loved one in the last five years are more likely to have made plans relating to their will (48% compared to 37% of people who have not lost someone in this time), their funeral (30% and 22% respectively) and a living will (11% and 4% respectively). Moreover, age does not appear to be an over-riding factor, as recent experience of death is broadly consistent across age groups.
When prompted with three scenarios that might encourage them to make plans for their death – making it easier for family, ensuring the right care and support is in place and having the funeral that they wanted – more (79%) say that lessening the burden on family is most likely to make them plan. Just under half (44%) would also plan to help ensure that they have the right care and support whilst dying.

Encouraging people to make plans

Q16. If you knew you did not have long to live, which of these would be most likely to make you start planning for your death? [multicode]

- To make my death/dying easier for my family: 79% East of England, 77% Rest of England
- To ensure I had the right care and support when I am dying: 44% East of England, 48% Rest of England
- To have the funeral I wanted: 24% East of England, 27% Rest of England
- Other: 6% East of England, 6% Rest of England
- None of these: 2% East of England, 3% Rest of England

Women are more likely to be concerned about making their death/dying easier for their families (83% compared with 77% of men) and also that they get the right care and support (51% compared to 38% of men). People who live with a long-term condition are more likely, than those without a long-term condition, to plan if they knew it would help them get the right sort of care and support (51% versus 43% of those without a long-term condition).

When asked about information or support needed to make plans, more agree that easy access to information about how to plan would help them take action (76%), rather than support from someone to help write an end of life care plan (67%).
People aged over 75 are the age group most likely to disagree that support in writing a living will would help them plan.

When asked, without any prompting, if anything else would help them plan if they did not have much time left to live, over three quarters of respondents (77%) did not give a response. This perhaps suggests there is either limited desire for additional support, or that there is limited knowledge of what might help them plan.

Of those giving an answer, the most commonly given response is for some form of advice, mentioned by six per cent of people. Within this, financial advice (2%) is the single most cited area of guidance required.

**Preferred sources of information**

When asked who they would prefer to receive planning information from, should they not have long left to live, the most common answers are friends/family (54%), followed by a doctor/GP (47%). One in five (20%) would seek it from their solicitor, while one in six (17%) would be happy to receive it from a nurse. Although 74% of respondents say they follow a religion or belief system (including those not currently practising), just one in ten (10%) say they would like this information from a religious or spiritual advisor.
This is in line with the results of the NCPC survey and broadly similar to the preferences of people elsewhere in the country.

**Preferred sources of information**

Q19. Who would you like to give you information about planning if you did not have much time left to live?

<table>
<thead>
<tr>
<th>Source</th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friend/family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor/GP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solicitor</td>
<td>20%</td>
<td>17%</td>
</tr>
<tr>
<td>Nurse</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>The internet</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>Religious or spiritual adviser, such as vicar, priest, imam or rabbi</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td>Funeral Director</td>
<td>9%</td>
<td>11%</td>
</tr>
<tr>
<td>Independent financial advisor/Bank manager</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>4%</td>
<td>4%</td>
</tr>
</tbody>
</table>


Women are more likely than men to want to get this information from a nurse (23% compared to 12% of men), while people aged 75 or over are the least likely age group to want to receive it from a healthcare professional (41% compared to 53% overall). People with children under the age of 17 are more likely than average to want to receive this information via a nurse (24% versus 17% overall). People aged 55-64 are the age group most likely to prefer this information coming from family or friends (64% compared to 54% overall).

**Ability to plan**

The majority of people (81%) say they feel confident in being able to plan for their funeral, but there is less confidence in planning for financial support (66%) and getting the right sort of care and support (62%) if they did not have long left to live. Around a third are not very or not at all confident they could plan to get the right sort of care and support (36%), or for financial support (31%). There appears to be a greater degree of confidence in the Eastern region than elsewhere in the country in planning for funerals (81% compared to 74%).
Confidence in making plans

Q27. Firstly, how confident do you feel that you could plan to get the right sort of care and support if you did not have long to live?

Q28. How confident do you feel that you could plan for your financial support if you did not have long to live?

Q29. How confident do you feel that you could plan your funeral arrangements?

<table>
<thead>
<tr>
<th></th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care and support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Very confident</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>% Fairly confident</td>
<td>49</td>
<td>50</td>
</tr>
<tr>
<td>% Not very confident</td>
<td>30</td>
<td>29</td>
</tr>
<tr>
<td>% Not at all confident</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>% Not stated</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Very confident</td>
<td>16</td>
<td>19</td>
</tr>
<tr>
<td>% Fairly confident</td>
<td>50</td>
<td>49</td>
</tr>
<tr>
<td>% Not very confident</td>
<td>23</td>
<td>21</td>
</tr>
<tr>
<td>% Not at all confident</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>% Not stated</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>East of England</th>
<th>Rest of England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funeral arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Very confident</td>
<td>32</td>
<td>22</td>
</tr>
<tr>
<td>% Fairly confident</td>
<td>49</td>
<td>52</td>
</tr>
<tr>
<td>% Not very confident</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>% Not at all confident</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>% Not stated</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>


As shown in the following chart, men in the East of England are more likely than women to be confident about making plans for their financial support, funeral arrangements or care and support.
Confidence in planning - by gender

Q29. How confident do you feel that you could plan your…..?

<table>
<thead>
<tr>
<th>Service</th>
<th>Very/fairly confident (men)</th>
<th>Very/fairly confident (women)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care and support</td>
<td>69%</td>
<td>58%</td>
</tr>
<tr>
<td>Financial support</td>
<td>74%</td>
<td>63%</td>
</tr>
<tr>
<td>Funeral arrangements</td>
<td>87%</td>
<td>79%</td>
</tr>
</tbody>
</table>

Preferences for end of life care
Preferences for end of life care

This section discusses preferences for end of life care – where people would prefer to die, care and support required to die at home, and the most important aspects of care.

The key findings of this chapter are as follows:

- When asked to indicate their preferred place to die, the most common answer is ‘at home’ (55%) followed by one in six who say it would depend.
- The majority of respondents prioritise receiving the correct care and support over dying in the place of their choice.
- Being with friends and family and being pain free are prioritised as the most important factors in end of life care.
- A large majority of respondents say that they would want to be informed of a terminal diagnosis, although one in seven (15%) of people aged 75 or older would prefer not to know.

Preferred place to die

A slight majority (55%) say that their preferred place to die would be at home. Following this, the most commonly given answer is that it would depend on the circumstances (17%). One in nine (11%) would prefer to be in a hospice, while six per cent say they do not mind. Just two per cent would choose to die in a care home, whilst three per cent say that a hospital would be their preferred place of death. Four per cent would prefer to be somewhere other than the locations listed.
Of those aged 75 or over, seven in ten (69%) would prefer to die at home. This is by far the most common answer given by this age group, with the second highest choice being in a hospice, selected by just 10%. Women (24% compared to 10% of men) and people who prioritise being with their family or friends as the most important factor of their end of life care (24%) are more likely to say that it depends on the circumstances.
Q20. Thinking about yourself, where do you think would be the best place to die?

<table>
<thead>
<tr>
<th></th>
<th>% At home</th>
<th>% In a hospital</th>
<th>% In a hospice</th>
<th>% In a care home</th>
<th>% Somewhere else</th>
<th>% Don't mind</th>
<th>% It depends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>58%</td>
<td>4%</td>
<td>12%</td>
<td>3%</td>
<td>4%</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>Female</td>
<td>53%</td>
<td>3%</td>
<td>11%</td>
<td>3%</td>
<td>4%</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>16-24</td>
<td>50%</td>
<td>8%</td>
<td>5%</td>
<td>12%</td>
<td>25%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>57%</td>
<td>2%</td>
<td>10%</td>
<td>15%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35-54</td>
<td>57%</td>
<td>1%</td>
<td>4%</td>
<td>3%</td>
<td>5%</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>48%</td>
<td>7%</td>
<td>18%</td>
<td>4%</td>
<td>6%</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>53%</td>
<td>12%</td>
<td>17%</td>
<td>3%</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>75+</td>
<td>69%</td>
<td>2%</td>
<td>10%</td>
<td>3%</td>
<td>3%</td>
<td>7%</td>
<td></td>
</tr>
</tbody>
</table>

The majority (68%) of respondents who want to die at home say that their wishes would remain unchanged even if medical or social care was not immediately available. Less than a third (29%) say that in those circumstances their wishes would change. The support of friends or family is considered more important, however; if the support of family or friends was not available, almost two thirds (64%) would no longer want to die at home.
Care and support needed to die at home

Q21. Would you still prefer to die in your own home even if medical or social care was not immediately available if you needed it?

Q22. Would you still prefer to die in your own home even if you did not have any support from family or friends?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Not stated</th>
</tr>
</thead>
<tbody>
<tr>
<td>68%</td>
<td>29%</td>
<td>2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Not stated</th>
</tr>
</thead>
<tbody>
<tr>
<td>64%</td>
<td>32%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Base: 371 adults living in the East of England who would prefer to die at home, fieldwork dates 26th March – 20th July 2010

Key aspects of end of life care

When asked to prioritise between receiving the care and support that they want and dying in the place of their choice, the majority of respondents attach more importance to their care and support (59%) than being able to die in their preferred location (37%).
End of life preferences

Q23. Thinking about yourself, when the time comes, which of these two options would be more important to you?

- To die in the place of my choice (37%)
- To get the care and support I want (59%)
- Not stated (5%)

There is a gender difference within this choice, however; men are more split on which is more important with just over half (56%) stating it is receiving the care and support they want, and two in five (43%) to die in their chosen place. Women, on the other hand, are more likely to choose care/support (64%) over the location of death (33%).

When prompted with the following list, respondents say that the two most important factors in their end of life care are to be with family and/or friends and to be without pain (79% and 77% respectively). However, other considerations including peace and calm, dignity, not being a burden and to have wishes listened to, are all rated as important by more than six in ten.
When asked which is the single most important aspect of their end of life care, the most common response is to be with family or friends (31%), followed by a pain-free death (27%). Around one in ten prioritise dignity (10%), not being a burden on others (10%), having their wishes respected (9%) and peace and calm (9%).
Most important aspects of end of life care

Q26. And which one would be most important?

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>To be with family or friends</td>
<td>31%</td>
</tr>
<tr>
<td>To be peaceful/calm</td>
<td>9%</td>
</tr>
<tr>
<td>To be sure that I am not a burden on other people</td>
<td>10%</td>
</tr>
<tr>
<td>To keep my dignity</td>
<td>10%</td>
</tr>
<tr>
<td>To be pain free/without pain</td>
<td>27%</td>
</tr>
<tr>
<td>For people to listen to and respect my wishes</td>
<td>9%</td>
</tr>
</tbody>
</table>


This is broadly in line with the results of the Dying Matters Coalition survey, which also found that being with family and friends was the most valued aspect of end of life care, (25% cited this), followed by a pain free death and retaining dignity (both 23%).

Sub-group differences of particular note include:

- Women attach a particular level of importance to being with family and friends (37% compared to 26% of men);
- Those of a younger age prioritise being with family or friends (44% of 16-34 year olds compared to 31% overall);
- Those aged 65+ are most likely to select being pain free (37%), while people aged 75+ are the age group most likely to fear being a burden on others (18% versus 10% overall).

A large majority (87%) of respondents say that they would like to be told if they were terminally ill, with just 8% saying that they would prefer not to be informed. This is comparable to the results of the NCPC survey, in which 88% said that they would like to be informed of a terminal prognosis.
More men (93%) than women (86%) would want to know. Just over one in seven (15%) people aged 75 and over would prefer not to know.

People who say they are comfortable in discussing death are also more likely to be open to receiving this information (92%), yet still seven in ten (69%) who find it uncomfortable talking about death would want to be told.

**Being informed of a terminal diagnosis**

Q24. If you were terminally ill, would you like to be told, or would you prefer not to know?

- **Would want to be told**: 87%
- **Would prefer not to know**: 8%
- **Not stated**: 4%

Appendices
Appendices

Statistical reliability

The respondents who took part in this survey are only a sample of the total "universe" of those who could have taken part, so we cannot be certain that the figures obtained are exactly those we would have found if everybody had responded (i.e. the "true" values). We can, however, predict the variation between the sample results and the "true" values from knowledge of the size of the samples on which the results are based and the number of times a particular answer is given. The confidence with which we can make this prediction is usually chosen to be 95% - that is, the chances are 95 in 100 that the "true" value will fall within a specified range. The table below illustrates the predicted ranges for both the East of England and national samples and percentage results at the "95% confidence interval".

<table>
<thead>
<tr>
<th>Size of sample on which survey result is based</th>
<th>Percent giving response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10% or 90%</td>
</tr>
<tr>
<td>East of England (693)</td>
<td>± %</td>
</tr>
<tr>
<td>Rest of England (332)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

For example, with a sample size of 693 where 30 per cent give a particular answer, the chances are 19 in 20 times that the "true" value (which would have been obtained if the whole "universe" had been interviewed) will fall within the range of +/- 3 percentage points from the survey result (i.e. between 27% and 33%).

When results are compared between separate sub-groups within a sample, different results may be obtained. The difference may be "real," or it may occur by chance (because not everyone in the universe has been interviewed). To test if the difference is a real one - i.e. if it is "statistically significant", we again have to know the size of the samples, the percentage giving a certain answer and the degree of confidence chosen. If we assume "95% confidence interval", the differences between the results of two separate groups must be greater than the values given in the following table:

Differences required for significance at or near these percentage levels
<table>
<thead>
<tr>
<th>Size of samples compared</th>
<th>10% or 90%</th>
<th>30% or 70%</th>
<th>50%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>±%</td>
<td>±%</td>
<td>±%</td>
</tr>
<tr>
<td>693 (East of England) versus 332 (rest of England)</td>
<td>4</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Male (224) versus female (447)</td>
<td>5</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Aged 35-54 (235) versus 55-64 (103)</td>
<td>7</td>
<td>11</td>
<td>12</td>
</tr>
</tbody>
</table>
Questionnaire